

A Survey for Family Members of Youth Mental Health Clients Regarding Personal Health Records (PHRs) that Include Both Physical and Mental Health Information

Please help the California Department of Mental Health by providing your input about Personal Health Records (PHRs) and what guidelines might be needed for their use.

For each question, mark the answer that corresponds to your choice. Please fill in the circle completely.

EXAMPLE: Correct ☐ Incorrect ☒ ☒

Demographic Information:

1 Gender of child(ren) receiving mental health services (if more than one, mark all that apply):

☐ Female ☐ Male

2 Age of child(ren) receiving mental health services (if more than one, mark all that apply):

☐ 0 - 5 years ☐ 6 - 15 years ☐ 16 - 17 years

3 Race/Ethnicity of your child(ren) receiving mental health services (mark all that apply):

☐ White / Caucasian

☐ Asian

☐ Other:

☐ Black / African American

☐ American Indian / Alaskan Native

☐ Hispanic

☐ Native Hawaiian / Other Pacific Islander

4 Please indicate which personal experiences you have that are most relevant for this survey (mark all that apply):

☐ Mental Health Client

☐ Family member or caregiver of a minor age mental health client

☐ Other (please specify):

Current Use of Email with Your Child's Service Providers:

5 Please indicate below when (if at all) you use email to communicate with one or more of your child's service providers (mark all that apply):

☐ Not at all because I don't have email.

☐ Not at all because none of my child's service providers offer this way of communicating with them.

☐ Not at all because I don't trust emails to be secure enough to keep my child's information private.

☐ Sometimes with my child's medical doctors or their assistants.

☐ Sometimes with one of my child's mental health service providers.

☐ Frequently with my child's medical doctors or their assistants.

☐ Frequently with my child's mental health service providers.



Getting Information Into Your Child's PHR:

6 Please indicate what types of information you might want included in your child's PHR (mark all that apply):

- ☐ Medications my child takes and the side effects he or she experiences
- ☐ Diagnoses my child has been given
- ☐ My child's allergies and types of reactions
- ☐ Recent lab and other test results
- ☐ Emergency contact information
- ☐ Lists of current treatments and related services my child receives
- ☐ Summary of my child's previous illnesses and the treatment(s) he or she received for them
- ☐ Family history
- ☐ Current insurance coverage
- ☐ My child's address, phone number and birth date
- ☐ Physical and mental health information from other child-serving departments and agencies like social services, education, juvenile justice
- ☐ Other (please specify):

7 There are several ways you might bring information into your child's PHR. Please indicate which ones you think you would use (mark all that apply):

- ☐ I give permission for my child's service providers or others who have some of my child's health care information (e.g., pharmacy, health plan) to directly enter information that I request from my child's records into my child's PHR.
- ☐ I give permission for my child's service providers or others who have some of my child's health care information (e.g., pharmacy, health plan) to automatically enter updates into my child's PHR without me having to ask each time they have new information.
- ☐ I ask for printed copies of whatever information I request from my child's records so that I can type it into my child's PHR.
- ☐ Other (please specify):

8 You can also enter your own comments directly into your child's PHR. Listed below are some of the ways you can do so for your family's private use or to share with others. Please indicate which of these you think you might want to use (mark all that apply):

- ☐ I would write comments about what my child's service providers wrote in my child's chart that was then included in his or her PHR.
- ☐ I would jot down questions to ask my child's service providers and record their answers.
- ☐ I would list my child's recovery and wellness goals and plans.
- ☐ I would track my child's thoughts, feelings and behaviors related to their treatment.
- ☐ I would note and track my child's triggers for mental health problems.
- ☐ I would write information I need to remember about my child's health care benefits and payments.
- ☐ Other (please specify):



Sharing Your Child's PHR Information with Others:

9 Listed below are some situations when you might need to share your child's physical or mental health information with others. If you kept a PHR, you could give permission for others to view parts of your child's PHR instead of trying to remember the information and filling out forms. Please indicate below when you think a PHR would be useful if your child had one (mark all that apply):

- ☐ My child is about to begin services with a new provider and I send basic registration information to their office from my child's PHR online before the first visit instead of filling out forms later at their office.
- ☐ One of my child's treatment providers asks for a summary of medications, lab test results, or other treatments my child received from his or her other general health care providers, and I let my child's treatment provider view that information in my child's PHR.
- ☐ My child is about to start receiving services from another child-serving department or agency, they ask for a summary of treatments my child received from other providers, and I let them view that information in my child's PHR.
- ☐ My child has an accident, is in the emergency room, the attending doctor asks for basic information about my child's health history and current treatments, and I tell the doctor how to get that information from my child's PHR.
- ☐ I want one of my child's service providers to review recent personal notes I made in my child's PHR about his or her physical or mental health condition.
- ☐ I want a family member or close friend to review a summary of my child's recent services or personal notes I made in my child's PHR about his or her physical or mental health condition.
- ☐ I am one of many people asked periodically to respond to a privacy-protected population study of public health conditions related to children conducted by a public health agency, and I give permission for them to get the selected data they request from my child's PHR.

Protecting Your Child's PHR Information:

10 The privacy of your child's physical and mental health information must be protected. What kind of security protections for your child's PHR would you prefer? (mark all that apply):

- ☐ I create a password and give it to whomever I want to be able to see my child's PHR.
- ☐ I arrange for my child's PHR service provider to divide my child's health care record into sections according to how private I think the information should be, create separate passwords for each section, and give a person the password for only the section I want that person to see.
- ☐ I prearrange for emergency care providers to bypass my password protections if there is an emergency in which I can't provide the password and my child's health may be in immediate danger.
- ☐ I create a password for public health agencies to use periodically to obtain selected data from my child's PHR, without them using my child's name, as part of their ongoing effort to study public health trends and prevent or manage epidemics related to children.
- ☐ Other (please specify):



Other PHR Services:

- 11** In addition to a record of your child's personal health, a PHR usually provides other services. Several of them are listed below. Please indicate which ones you think you might want to use (mark all that apply):
- ☐ Get general information about physical health conditions my child might be experiencing, and recommended treatments for them.
 - ☐ Get general information about mental health conditions my child might be experiencing, and recommended treatments for them.
 - ☐ Get general information about psychiatric medications, including those my child might be taking.
 - ☐ Get general information about non-medication services for mental health conditions, including those services my child might be receiving.
 - ☐ Exchange secure, privacy-protected emails with my child's service provider about my child's condition and treatment.
 - ☐ Check my child's service provider's appointment schedule online and schedule an appointment.
 - ☐ Receive timely notification of product warnings or recalls regarding the medications my child is taking.
 - ☐ Other (please specify):

Supporting PHR Services:

- 12** Several types of organizations are listed below that offer PHRs and related services. Please indicate from which ones you would feel comfortable receiving these services for your child (mark all that apply):
- ☐ My employer (if applicable)
 - ☐ My child's health plan (if applicable)
 - ☐ A government agency
 - ☐ My child's doctor or local hospital or clinic
 - ☐ An independent organization that provides PHRs and related services
- 13** How much would you be willing to pay for a PHR to help cover the costs of maintaining it and of supplying related services (mark all that apply):
- ☐ Not willing to pay anything
 - ☐ Willing to pay \$1 to \$5 per month
 - ☐ Willing to pay \$6 to \$10 per month
 - ☐ Willing to pay \$11 to \$15 per month
 - ☐ Willing to pay \$16 to \$20 per month

Potential Concerns, Help Needed and Suggestions:

- 14** Below is a list of the potential concerns people might have about PHRs for their children. Please indicate which ones might be a concern to you (mark all that apply):
- ☐ My child's PHR may not be secure and people who I don't want to see it may be able to do so.
 - ☐ People may be able to change my child's record without me giving them permission or even knowing about it.
 - ☐ The PHR and its services may be too complicated for me to use.
 - ☐ If I let my family or others see parts of my child's record, they may also be able to see the parts I don't want them to see.
 - ☐ If I let my service providers see parts of my child's record, they may also be able to see the parts I don't want them to see.
 - ☐ There may be more risk with computer records than paper records that people can review them who do not have my permission to do so.
 - ☐ Reviewing and managing my child's records may upset me.
 - ☐ I may have to pay beyond what I can afford for the PHR service and related computer services.
 - ☐ Other (please specify):



15 When you think about the kind of help you might need to make use of a PHR for your child, what types of help seem necessary? (mark all that apply):

- ☐ I do not have a computer and would need one provided to me either in my own home or in a location convenient to where I live.
- ☐ I do not have Internet service and would need it provided to me.
- ☐ I do not know how to work with a computer and would need training.
- ☐ I do not know much about PHRs and would need training so I could use my child's PHR effectively.

16 From what you now understand about PHRs, please indicate how useful you think it might be to you (mark only one):

- ☐ Useful ☐ Not Sure ☐ Not Useful

17 What other thoughts and comments do you have that we can pass on to those working on policies for the design of PHRs and their related services?

Thank you for responding to this survey. The results will be communicated to and considered by those who develop policies for PHRs and by those who design them.

PLEASE MAIL YOUR COMPLETED SURVEY BY MARCH 15, 2007, TO:

California State Department of Mental Health
Performance Outcomes & Quality Improvement Unit
1600 9th Street, Room 130
Sacramento, CA 95814

